



## **Connecting Minds – Dementia Care Newsletter**

**Wisconsin Bureau of Aging and Long Term Care Resources**

Cathy Kehoe, Alzheimer's Service Developer

*The Wisconsin Bureau of Aging and Long Term Care Resources received in July 2000 an **Alzheimer's Demonstration Grant** from the **Federal Administration on Aging** to improve quality of, and access to, long term care services for people with Alzheimer's disease and related dementia across the state. As part of the grant, **Cathy Kehoe, Alzheimer's Service Developer**, issues this quarterly newsletter for people who work in the long term support system.*

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### **Food for Thought: Care Planning for People with Alzheimer's Disease**

Take a moment to close your eyes and picture what it would be like for you to be in the early stages of Alzheimer's disease. Imagine that you knew you would have five years warning before the disease set in.

What would you want your life to be like?

How would you want to be cared for?

Who would you want to be your caregiver?

Where would you want to live?

What important things would you do that you'd been putting off?

How would you insure that these things would happen for you?

Now consider the role of your case manager and other professionals working with you.

What would you convey to them about **you**?

This exercise emphasizes the importance of knowing the *person* when gathering information to create that person's care plan. Consider lifelong habits, routines, rituals and activities that are dear to the person. If you can insure that these things remain part of his life, the person you work with will have an enhanced quality of life and higher level of function for longer.

**Consider the following bill of rights as a guide for quality of life care planning:**

#### **Alzheimer's Disease Bill of Rights**

Everyone diagnosed with Alzheimer's Disease or a related disorder deserves:

- To be informed of one's diagnosis.
- To have appropriate, ongoing medical care.
- To be productive in work and play as long as possible.
- To be treated like an adult not a child.
- To have expressed feelings taken seriously.

### **Alzheimer's Disease Bill of Rights (cont.)**

- To be free from psychotropic medication if at all possible.
- To live in a safe, structured, and predictable environment.
- To enjoy meaningful activities to fill each day.
- To be out of doors on a regular basis.
- To have physical contact and affection.
- To be with people who know one's life story, including cultural and religious traditions.
- To be cared for by individuals well trained in dementia care.

*Adapted from: Bell VM & Troxell D. An Alzheimer's Disease Bill of Rights, 1994*

**Informing a person of her diagnosis** has two important aspects to it. First, it is vital to get a thorough and correct diagnosis as a first step to any good care plan. This will rule out any health or medication issues that may be causing a reversible condition. It also gives a person access to the new medications that people with Alzheimer's are benefiting from. The earlier in the disease the person is diagnosed, the better off they are on the new medications. The second reason to inform her of the diagnosis is so that she can make plans to enjoy the things she can still do, and put important future measures in place such as advanced directives and choices for her quality of life.

**Appropriate, ongoing medical care** not only involves having the right diagnosis, it also means addressing issues such as pain, safety, vision and hearing difficulties, and driving issues. All of these things impact the life quality of a person with Alzheimer's disease. Be sure you take include assessment of these things in the care plan, particularly when addressing behavior and communication problems. The physician can be an ally in addressing driving issues. He can order an Occupational Therapy evaluation to determine safety, and can legally report driving issues to the state whereas family members can't.

**Remaining productive in work and play as long as possible** is perhaps the most important key to quality of life. Realize that the person with Alzheimer's disease knows that there is something wrong, and that he is afraid of losing the very activities and usefulness that may help define who he is. In our day and age, people are often defined by what they do. Consider ways to keep him involved - in any way possible - with activities that reflect his talents, hobbies, work habits and core personality traits such as being a "giver", "helper" or "mentor". To incorporate this into the care plan you will need to do a very detailed social history – interviewing people in his life for information too. You will need to include them as partners in planning meaningful activities, and impress upon the caregivers how important it is to keep the person active.



**Treating a person with dementia like an adult not a child**, can be a challenge. Not only is this person we knew slowly fading, but we have all been trained to "parent" people we care for. It is essential that we realize that the person with dementia cannot learn the way a child does. Many parenting approaches – such as setting limits or consequences, trying to change behavior, or correcting – simply are not effective and set both people up for frustration. Instead, respect the person with dementia's dignity and life experience. You may need to model this to the caregivers, and refer them to the Alzheimer's Association chapter for caregiver training.

**Taking a person with Alzheimer's disease expressed feelings seriously** may seem hard to do until you understand what the world is like for him. Because he is unable to remember things for even a few minutes, his surroundings may seem unfamiliar. This can cause frustration, anger, fear or a longing to "go home" or be with (long dead) parents. Taking these feelings seriously means trying to address the need behind them. Sometimes reassurance, a familiar activity, or directing conversations to fond memories may be very effective in helping the person feel "listened" to and comfortable. Consider ways to model this and educate caregivers on the art of hearing the needs behind words that often don't make sense.

**Being free from psychotropic medication if at all possible** is important. Sedating a person with Alzheimer's disease leads to rapid decline and loss of function. There are many effective alternatives that can be exhausted first. A solid problem solving approach to behavior challenges is a must. You will need to be a creative investigator when helping caregivers solve behavior problems. It is estimated that most behavior problems are caused by the environment. Documenting the times of day, people present, associated activities such as people coming and going or meals cooking etc. is the first step to understanding what the person is experiencing. Altering the environment or simultaneous activities can influence behavior dramatically. Dehydration is also a cause of behavior problems. Always get a medical evaluation for illness, pain, medication reactions or hearing/vision problems to uncover physical things that are causing behavior problems. In addition, new medications on the market for dementia are not sedating, and can have a profound effect on behavior. Be sure the person's physician is knowledgeable about the medications, and if not, find a specialist who is. Knowing one or two really good dementia physicians will help you enormously. Some people literally need a medication holiday in a treatment setting to determine what their level of function really is.

**A safe, structured, and predictable environment** keeps the person with Alzheimer's disease involved with life. It is the foundation of him being able to maintain skills and independence on any level. Without structure and predictability, he will become agitated, fearful, distraught, lethargic, bored and more confused. In the care plan, help caregivers plan and adhere to a meaningful routine. Is the person having trouble sleeping? Perhaps she needs to say the rosary as she did each night for years, in order to cue her body into the time for sleep. For daytime activities, consider replicating the person's former work-day and place.



**The enjoyment of meaningful activities to fill each day** includes **being out of doors on a regular basis**. Walking and maintaining muscle strength is imperative to preventing falls and remaining healthy – mentally and physically. When choosing facilities for people with dementia, consider the ability to safely walk outside and perhaps do things like gardening. Both of these "rights" involve feeling a sense of well-being, as well as **having physical contact and affection**. The person with Alzheimer's disease communicates a lot through touch as their other means of communicating dwindle.

**Being with people who know one's life story, including cultural and religious traditions** allows the person with Alzheimer's disease to stay in touch with who he is. Because he cannot remember present events, his "present" is actually his memories of the past. This is why it is so essential to use as many natural support people in the person's life as possible to deliver care. How can you plan to keep him involved with his church, neighborhood and fishing friends?



**Being cared for by individuals well trained in dementia** care means that the caregiver knows the person can't learn anymore. Good caregivers provide opportunities for her to use the skills she still has, honor her memories of the past without correcting them, enter her world with her and listen to the emotional needs behind her words. Family caregivers must receive training and support in order to understand and use these skills. Be sure that whatever professional caregivers you use have dementia training too.

## Solving Problem Behaviors: Wandering and Agitation

According to a recent study of people with Alzheimer's disease, wandering is more likely to occur as the result of anger or agitation. Underlying causes of the agitation include:

- Person is not feeling well and is unable to express it.
- Person may have to go the bathroom and may not know where to go.
- Person feels an urgent need to do something that was part of their routine in the past.

When a person with dementia experiences the present – they are who they remember being in the past. By getting a picture of the person in their previous life you may be able to solve or ward off behavior that is problematic. Did she enjoy precious moments watching the birds in the morning, or was the day not complete until she had her purse next to the bed? Something as simple as a bed-time or meal-time ritual can change a person from being agitated and searching to clueing into a calming routine from their previous life. If the person with dementia is to be happy and free of agitation, familiar things must be the anchor to the life that he barely recognizes anymore. The care plan can reflect these unique aspects. In one wandering and agitated gentleman the care manager created a work-day space and schedule, complete with lunchbox, for the man who faithfully never missed a day of work in 20 years. He never wandered again and remained at home for years.

### **Other Wandering Strategies:**

Perception and association are keys to remember with wanderers. In addition to keeping the person engaged in meaningful activities, altering the environment is another important strategy.

- Keep coats, hats, outdoor shoes put away. These cue the person that it's time to leave.
- Disguise doors to look like something else with colorful murals, drapes or by blending them with walls.
- Keep a dark colored mat in front of the door. People with dementia experience diminished perception of floor surfaces and see dark colors as holes where they won't step.
- View the wandering study on the web:  
<http://www.post-gazette.com/healthscience/20011030hwander3.asp>  
<http://www.post-gazette.com/healthscience/20011030hwandertips.asp>

### **Nifty Products on the Web for Wanderers:**

Looking for some great ideas to make a home "dementia friendly"? Go to [www.thealzheimersstore.com](http://www.thealzheimersstore.com) 1-800-752-3238

You can find a large assortment of products designed to make life easier and more independent for a person with dementia, and for caregivers. Featured alarm products include door and window alarms, motion detectors, and murals to cover doors so they aren't even perceived. Also featured is an excellent new book:

***"The Complete Guide to Alzheimer's Proofing Your Home"*** by Mark Warner.

Other products for home use for wanderers include various types of door and window alarms, proximity alarms where the caregiver has a pager that goes off when the person with dementia gets a certain distance away, chair alarms, and personal tracking systems locating people by satellite.

- [www.wireless-concepts.com](http://www.wireless-concepts.com). 1-800-582-9000 [www.digitalangel.net](http://www.digitalangel.net): 1-651-455-1621
- [www.store.yahoo.com/alzheimersolutions](http://www.store.yahoo.com/alzheimersolutions): 1-215-624-2098
- [www.seniortechnologies.com](http://www.seniortechnologies.com) 1-800-206-1044 [www.nowander.com](http://www.nowander.com), 1-800-606-0661
- [http://seattletimes.nwsourc.com/html/localnews/134362019\\_lifesaver03m.html](http://seattletimes.nwsourc.com/html/localnews/134362019_lifesaver03m.html)

### **Safe Return Program – A Must for Caregivers:**

The safe return program is a system designed to work with local law enforcement to return a person with dementia safely home if she becomes lost in the community. Always register any person with dementia who wanders with the **Alzheimer's Association Safe Return Program** accessible through any local Alzheimer's Association Chapter. For more information go to <http://www.alz.org/caregiver/programs/safereturn.htm>



## Demonstrating a Wisconsin Dementia Service Network

The BALTCR and partners are beginning the second year of a three year grant to improve services for people with Alzheimer's Disease and Related Dementia in Wisconsin. Two priority areas were described in the proposal funded by the Administration on Aging (AoA). The Southeastern Wisconsin project intends to strengthen linkages between health and social service professionals serving minority and under-served persons with dementia through enhanced referral systems, early screening and diagnosis, outreach, education, family support and through the provision of some direct services for persons with dementia. Sharon Beall, BALTCR Nurse Consultant manages the AoA grant; she and Sig Tomkalski, Executive Director of the Alzheimer's Association Southeastern WI Chapter, are co-coordinators of the Southeastern project.

In April 2001, Cathy Kehoe, Alzheimer's Service Developer was hired by the Bureau to lead statewide activities to examine barriers to services and promote best practice models for persons with dementia receiving community-based long term support services. Statewide activities include addressing barriers to service identified through examining data, interviewing, examining processes and care plans, and connecting with key people and agencies in the long term care system such as the Alzheimer's Association Chapters and Wisconsin Alzheimer's Institute. Current projects include:

- Grant writing to develop and implement pilot dementia response teams in select counties/regions.
- Developing dementia specific training for Adult Family Home providers.
- Coordinating an advisory committee to develop quality outcomes for people with dementia receiving long-term support services.
- Participation on the Adult Protective Services Modernization Project to ensure that dementia is reflected in state statutes and connecting resources and people across the state to address specific dementia issues.

**Each newsletter will feature creative initiatives in Alzheimer's and Dementia care from across the state.** Please tell us what you are doing!!!

Ideas for future newsletter topics are welcome.

**Submit your contributions to:**

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